

# *Caring Today, Planning for Tomorrow*



NATIONAL ALLIANCE FOR CAREGIVING

THE EQUITABLE  
FOUNDATION



National Alliance for Caregiving  
in collaboration with the  
General Federation of Women's Clubs,  
Business and Professional Women/USA, and  
the Employee Assistance Professionals Association

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# *Part One — Caregiving for Your Older Relative*

## *Introduction*

The United States is undergoing what many experts refer to as a longevity revolution. Not only are people living longer now than in the year 1900, we are living longer in old age. For example, in 1940 there was about a 7% chance that a 65-year-old would live to age 90. By the year 2000, the estimate could more than triple to 26%<sup>1</sup>.

But living longer does not always mean living healthier. One of the increasingly important – but less recognized – consequences of the longevity revolution is the change in the need for long-term care. Many people reading and using this guide are family caregivers. Others anticipate becoming caregivers of an older relative in the near future. Almost 80% of all the care provided to older people is “informal,” that is, provided by family members or other unpaid volunteer caregivers in the home rather than by caregiving professionals or institutions<sup>2</sup>. Benefit programs for those over 65, such as Medicare, provide very little financial assistance for long-term care, especially in the home. This is part of the reason why family caregivers step in when needed, often providing multiple care services for a much longer period than they anticipated.

There's another important aspect of caregiving: While you are providing care for others, you should also be preparing for your own future health, financial, and long-term care needs. We've all heard of the “sandwich

generation.” Whether or not you are truly sandwiched between taking care of both young children and aging parents, or are only providing care for an older person, you still have the joint responsibility for the elders – and for yourself. Over the past few years, the National Alliance for Caregiving (the “Alliance”) has conducted several national studies of caregivers and caregiving. One of the major findings is that caregivers desire information, education, and resources on the financial and health aspects of caregiving. Equally important, caregivers need and want information to help them plan for their own future needs in the areas of finance and long-term care.

The aim of this resource guide for caregivers is to introduce you to a broad array of subjects that can be helpful to you as a caregiver. In preparation for this guide, the Alliance conducted a Baby Boomer women caregivers' survey and then held a series of focus groups with members of the General Federation of Women's Clubs, the Business and Professional Women/USA, and the Employee Assistance Professionals Association – its partner organizations for this project. In response to the survey and the focus group requests, we developed the guide in two parts. The first part of the guide covers areas which can help you as caregiver of others, while Part Two concentrates on helping you in planning for your own

future needs. In this guide, we provide you with a basic introduction to each subject, show its connection to other topics and to caregiving tasks, and identify key resources where you can turn for further study and information. Caregiving and planning for your own needs are difficult tasks. This guide can be a valuable tool to assist you in both areas.

## *Caregiving's Challenge*

### *Health Issues*

Caregiving for an older relative, spouse, or other loved one usually starts for a health-related reason, whether from a crisis or the worsening of a chronic condition. Some of the most common health problems for people over 65 include arthritis, high blood pressure, heart disease, hearing impairments, cataracts, and mobility problems. Any one of these health conditions can create difficulty for an older person performing everyday activities such as walking, bathing, eating, dressing and other normal daily tasks which define their ability to live independently. When they require assistance with these "Activities of Daily Living" (ADLs), a spouse, relative, or friend usually steps in to assist by providing care themselves, arranging for care, or both.

Every caregiver wants to be able to provide as much care as possible, and often steps into an emergency situation. Regardless of the circumstances, one vital piece of information you need to know is the health status of your loved one. The important information

concerns their medical history, immediate medical problems, prescriptions and over-the-counter medications, and probable course of chronic illnesses.

The best place to start gathering information is with the care recipient's health care professionals – doctors, specialists, nurses, and pharmacists – who are currently providing health care services. Very often, they have gathered a full medical history as part of their treatment of your loved one and can fill in any information gaps you may have, and vice versa. Once you obtain the basic information (e.g., name, address, phone number), it's advisable to organize this information in one place that is easily accessible to you and other caregivers. If you're not familiar with these health providers, they are often identified on insurance invoices, Medicare bills, and other documents.

Once you have identified the health providers treating your relative, contact them and let them know you are involved with their patient. Important questions to ask include:

- What are the specific conditions or diseases for which they are providing treatment, including the current status of treatment, and prognosis for recovery or improvement? How long has the treatment been provided, and how long is it expected to continue?
- What are the implications of the condition for the lifestyle of the care recipient and the caregiver? Is it an

acute condition (a serious short-term condition) that will respond to immediate treatment, or is it a chronic condition (one that recurs frequently over a long period of time) that will require ongoing long-term care?

- What are the medications being prescribed, including dosage and schedule?

- What are sources of information and assistance regarding the condition being treated?

Even with these resources, however, it is often up to the caregiver to take an advocacy role for the care recipient with medical professionals, hospitals, or service providers. Physicians sometimes do not notice changes in the patient because of their intermittent contact with them. Or, they may miss distinguishing Alzheimer's Disease from other medically treatable forms of dementia. Find out if there is a geriatrician or a Geriatric Assessment Clinic nearby offering specialized diagnoses and services. The best entry to such a clinic is through the older person's general practitioner. If the patient belongs to a Health Maintenance Organization, there may be geriatric specialists within the group affiliated with the HMO. Pursue your questions and concerns with every agency or professional until you are satisfied with the answers (if necessary, be prepared to advocate with the care recipient's health care system for all the services they offer).

Many problems of old age are not natural or inevitable consequences of the aging process, even if they are associated with advanced age, and many of these problems can be dealt with if discovered early. With this basic information you should be able to develop a realistic assessment of the health issues facing the person you are caring for, and have a better understanding of the caregiving responsibilities you are facing.

### *Medicaid vs. Medicare*

Medicare is the national health insurance program for older (age 65+) Americans, paying for doctors' bills and associated services, and hospital and hospitalization services. All older men and women who are part of the Social Security system, no matter what their income or the size of their Social Security retirement benefit, are eligible for Medicare.

Medicare does not pay for the typical long-term care support services most people need. By contrast, Medicaid is a joint state-federal health insurance program for low-income people of all ages. For older people who do require chronic long-term nursing home residence and who have depleted their financial resources, Medicaid may pay the nursing home bills. Generally, this payment comes only after it has been certified that the older person does not have "sufficient" financial resources (usually less than \$2,000). Because each of the 50 States administers its own Medicaid program, the rules and

definitions of what are “sufficiently” low financial resources vary from state to state – as do the level of services provided and the amounts paid by Medicaid. Be sure to find out the eligibility rules in your older relative’s state. Medicaid also has very strict “spend down” requirements, often specifying how and when assets can be disposed of before Medicaid eligibility begins – in many cases, it can be as long as 2-3 years.

#### FURTHER INFORMATION:

- Basic elements of the Medicare program, its costs, lists of medical and health services that are covered and those that are not, can be found in the updated Medicare and You publication. This booklet describing basic Medicare rights and benefits is available in libraries, Social Security offices, most hospitals, and from the Medicare website: [www.medicare.gov/pubs](http://www.medicare.gov/pubs). The website offers an enormous amount of general and detailed information, as well as links to dozens of other governmental and informational websites relevant to elder health, health costs, and Medicare.

- Comprehensive Medicaid information and guidance is available on [www.hcfa.gov/medicaid](http://www.hcfa.gov/medicaid). The site provides detailed information on eligibility, services available, and state-specific differences for child health, elders, and services in general. A separate collection of information directly relevant to Medicaid support for long-term care services is also available:

[www.hcfa.gov/medicaid/ltchomep.htm](http://www.hcfa.gov/medicaid/ltchomep.htm).

### *Disease-Specific Information*

When asked what the most valuable piece of information they have obtained is, many caregivers cite information about the care recipient’s disease, such as what to expect, the stages of the disease, and how to care for someone with the disease. Of course, each caregiving situation is different, and you must be sensitive to the care recipient’s specific needs. Although caregivers are as diverse a group as those they care for, there are some common guidelines to follow in order to promote well-being, such as daily exercise, proper nutrition, and self-education (as these apply to individual situations). The following resources may help you learn about the assistance available for specific diseases/ conditions:

The National Health Information Center (NHIC) provides central health information referral services for consumers and professionals using a database of over 1,400 national associations, government agencies and other organizations. 800-336-4797

Healthfinder is an Internet site that links consumers and professionals to health and human services information. This site includes 4,000 resources on 1,000 topics which include aging, AIDS, cancer, heart disease, Medicare and Medicaid. [www.healthfinder.gov](http://www.healthfinder.gov).

The Wellness Interactive Network is a health resource directory with health care topics such as disease management and prevention, advice on nutrition and exercise, and a drug information database. [www.stayhealthy.com](http://www.stayhealthy.com).

The Alzheimer's Association is a voluntary organization that sponsors public education programs and offers supportive services to patient and families who are coping with Alzheimer's disease. 800-272-3900 919 N. Michigan Ave., Ste. 1100, Chicago, IL 60611. [www.alz.org](http://www.alz.org)

The American Cancer Society has local units which sponsor a wide range of services for cancer patients and their families, including self-help groups, transportation, programs and limited financial aid. 800-227-2345 1599 Clifton Rd., NE, Atlanta, GA 30329 [www.cancer.org](http://www.cancer.org).

The American Diabetes Association works to educate the public to recognize the warning signs of diabetes and to realize the importance of prompt treatment. The toll-free telephone service will provide information about diagnosis and treatment of diabetes and about resources available to people with the disease. 800-342-2383 1660 Duke St., Alexandria, VA 22314 [www.diabetes.org](http://www.diabetes.org).

The American Heart Association (AHA) distributes public education materials on the prevention and control of diseases of the heart and circulatory system. The AHA distributes a number of pamphlets for older adults including:

"After A Heart Attack" and "How You Can Help Your Doctor Treat Your High Blood Pressure." 800-242-8721 (call for nearest mailing address) [www.americanheart.org](http://www.americanheart.org).

The Arthritis Foundation has chapters nationwide that offer health education programs, self-help courses, exercise programs, support groups, public forums, and more. Local chapters provide general information and referral services. 800-283-7800 1330 W. Peachtree St., Atlanta, GA 30309 [www.arthritis.org](http://www.arthritis.org).

The National Hospice Organization operates a toll-free hospice referral line for terminally ill people. Individuals can contact NHO to learn about hospice services in their area. Materials are available on request. 800-658-8898 1901 N. Moore St., Ste. 901, Arlington, VA 22209 [www.nho.org](http://www.nho.org).

The National Multiple Sclerosis Society provides a wide range of services in the areas of education, information and referral, counseling, and public policy development and advocacy. 800-344-4867 733 3rd Ave., 6th Fl., NY, NY 10017 [www.dcnmss.org](http://www.dcnmss.org).

The National Osteoporosis Foundation distributes information about osteoporosis to people with the condition, their families, the general public, and health professionals. NOF offers continuing education programs and funds research. Newsletters are available. A list of materials is available on request. 202-463-7002 1232 22nd St, NW, Washington, DC 20037 [www.nof.org](http://www.nof.org).



Parkinson's Disease Foundation provides background literature, exercise materials, a quarterly newsletter, personal responses to written inquiries, and a physician referral service. 800-457-6676 710 W. 168th St., NY, NY 10032 [www.pdf.org](http://www.pdf.org).

### *Basic Care*

Caregivers provide a wide range of care to their care recipients. After disease-specific information, the National Alliance for Caregiving (NAC) survey and focus groups most requested information about basic care. Basic care may include information on feeding, bathing, keeping care recipients comfortable or helping them move around.

Although there is no single national training network, a variety of organizations and agencies provide education and training for caregivers. It may seem overwhelming for you even to contemplate finding the time for a training program, but some agencies offer respite (short-term relief for the caregiver of a frail person) or other programs to help you get training. Below are resources that can help caregivers to find education and/or training that can meet their needs. Please be advised that this is not a complete list. The Area Agency on Aging (AAA) in your county should be able to provide further information, if needed.

### FURTHER INFORMATION:

AARP sponsors educational programs at some local chapters. Local chapters are listed in the telephone directory or can be found by calling them directly. Publication lists are available upon request. 202-434-2277 601 E. St., NW, Washington, DC 20049 [www.aarp.org](http://www.aarp.org).

The federal Administration on Aging (AOA) offers programs to older people and their families in order to help meet their social and human service needs. The programs are offered through the nationwide network of Area Agencies on Aging (see below). Older people and their families can participate in a range of AOA supported services at the state and local levels including education, transportation, senior centers, and homemaker services. A list of publications is available upon request: AOA, Department of Health and Human Services, 330 Independence Ave., SW, Washington, DC 20201 [www.aoa.dhhs.gov](http://www.aoa.dhhs.gov).

The Eldercare Locator is a toll-free number, funded by the Federal Government, that provides the numbers to the nearest AAA or other aging services organization in the zip code where an older person lives. 800-677-1116. AAAs are aging offices in every county or multicounty area where older persons, their families, caregivers or anyone concerned about the welfare of an older person can obtain information on basic care and other topics as well as referral to services and benefits in their community. AAAs are listed in the telephone directory under

the city or county government heading.

Children of Aging Parents (CAPS) provides information and emotional support to caregivers of older people. CAPS serves as a national clearinghouse for information on resources and issues dealing with older people, especially support groups. Caregivers nationwide can contact the information and referral service to learn about local resources and programs. CAPS produces and distributes literature for caregivers. 800-227-7294 1609 Woodbourne Rd., Ste. 302A, Levittown, PA 19057 [www.careguide.net](http://www.careguide.net).

National Family Caregivers Association offers a website and newsletter and allows caregivers to share experiences. 800-896-3650 10605 Concord St., Ste. 501, Kensington, MD 20895 [www.nfcares.org](http://www.nfcares.org).

### *Medication Management*

Consumers have never had as much access to medications, especially over-the-counter (OTC) medications, as they have today. For many reasons, there is a new "era of self-medication" with many OTC medications now available which were formerly only available through prescription. This has helped reduce health care costs, but has also led to problems due to self-medication. Older adults report two to three minor chronic health problems, very often treated with over-the-counter medications. While both prescription and non-prescription medications are generally safe and effective, when

multiple medications are taken, as is often the case for older people, there is an increased likelihood of side effects or drug interactions that can cause additional health problems. In fact, this is one of the leading concerns that caregivers should be aware of. Getting medication regimens under control is not difficult, but usually requires some "detective" work by the caregiver, and consultation with a doctor.

Among the things to do are:

- Read all labels and directions for use, and all precautions and warnings for any medicine being used.
- Follow directions for use carefully, especially any special instructions on how to take the medication, or about other medications or foods to avoid.
- Get a current list of all medications being used. Check medicine cabinets, bedrooms, and kitchen cabinets where prescription and OTC medicines might be stored.
- Inform all health providers about medications being used, and keep a list of current medications handy for office visits to physicians, pharmacists, dentists, clinics, etc.
- Check medicine cabinets twice a year. Discard any expired medications, those not in their original container, and those no longer being used. One sure way to discard them is to flush them down the toilet.
- The bathroom cabinet may not be the best place for medications, which

usually require a cool, dry location. Be sure medicines needing refrigeration are stored properly.

- If you have questions, take the medicines to a doctor, pharmacist, or other health professional for information and assistance.

For further information about medication management you can contact:

American Society of Consultant Pharmacists. 703-739-1316 1321 Duke St., Alexandria, VA 22314 [www.ascpfoundation.org](http://www.ascpfoundation.org).

Consumer Healthcare Products Association 202-429-9260 1150 Connecticut Ave., NW, Ste., 1200 Washington, DC 20036 [www.chpa-info.org](http://www.chpa-info.org).

United Seniors Health Cooperative (202) 479-6973 409 Third St, SW, Ste 200, Washington, DC 20024 [www.ushc-online.org](http://www.ushc-online.org).

## *Legal Documents*

Sometimes caregiving involves legal issues related to the older person's "incapacity" (inability to care for him or herself) or "incompetence" (inability to understand the consequences of his/her actions). Getting legal assistance for completing some needed documents can ease the caregiving burden. These documents include a Durable Power of Attorney (DPOA) designating a person who can make decisions and act on behalf of the care recipient in property

and financial matters. Another type of DPOA is the Durable Power of Attorney for Health Care, or "health care proxy" allowing the designated agent to make medical decisions on behalf of the care recipient.

Other important legal documents include a valid will, an Advance Directive, and a Living Will. Advance directives specify treatments and medical procedures the care recipient prefers, while living wills specify medical care procedures in the event of a terminal illness or condition. These documents should be in the possession of the caregiver, with copies available for the physician, health institution, and family attorney.

Attorneys with specialized legal knowledge in the field of aging, advanced estate planning, and elder law can be located by contacting the National Academy of Elder Law Attorneys in Tucson, AZ (602-881-4005), or your local or state bar association lawyer referral service.

## *Caregiver Stress*

Family caregivers are subject to stress from a variety of sources – physical, emotional and financial. Although we hear a great deal about its negative effects, stress is a normal part of daily life. In fact, some stress is necessary for motivating us to act. However, too much stress can be detrimental to effective problem solving and eventually to our health and well-being. This is especially true in a caregiving

crisis. Under these circumstances, you may feel helpless and not know where to turn for help, or even what resources are available to assist you and your loved one.

### *Crisis Management*

How can you deal with the stress of a caregiving crisis? First, assess the situation realistically.

- Is the crisis immediate or an impending one in the near future?
- What are the circumstances contributing to your sense of crisis?
- What immediate support resources – family members, neighbors, friends who have experienced similar situations or feelings – are available to you?

One of the most effective responses to the stress of a crisis is to act to regain control of the situation.

Regaining control, reducing your stress level, and reacting effectively to a crisis can be as simple as gathering the information necessary to make sound decisions. This information includes:

- Health data: know medical history, prescriptions, medications; understand the immediate and long-term medical problems of the person you're caring for.
- Financial and legal information: know health and other insurance coverage; obtain power of attorney (if appropriate) and/or advance medical directives.

- Community services for both older people and caregivers: contact area agencies on aging, home health, or respite service providers.

- Governmental and benefit programs: determine Medicare/Medicaid coverage, long-term care insurance benefits.

First, determine how quickly you must act, what resources are available to you, and what information you need to deal with the immediate situation. Gaining some level of control over a crisis by stabilizing the caregiving situation and your own feelings and taking some action to resolve the crisis will all serve to reduce your stress.

Second, realize that you are not alone, and that there are resources to help you. It's quite normal to have conflicting feelings – guilt, denial, and even anger. By sharing your feelings, thoughts and concerns with others you can establish some areas of emotional support for yourself.

Third, take care of yourself, both physically and emotionally. It is especially important to remember that we get no formal training or preparation for being an adult caregiver for an older loved one, so don't be too hard on yourself – there is enough stress on you already!

### *Chronic Caregiver Stress*

The emotional and physical effects of stress can creep up on everyone. Be aware of the signs and symptoms of stress in yourself and with other caregivers so that you can seek some

relief when you or they need it.

Typical warning signs of stress include:

- Reduced attention span and concentration
- Reduced effectiveness at work or at home.
- Unusual or frequent memory lapses.
- Clear thinking and information processing are affected.
- Constant irritability, or dulled emotions.
- Physical aches and pains, irregular heartbeat, sweating, skin rashes, and/or stomach problems.
- Avoiding regular activities.
- Sleeplessness.

If you regularly experience any of these, stress may be catching up with you, and you should seek help, or be sure to have some ways of coping with the stress of caregiving. When caregivers experience stress very intensely, or over long periods of time, they may suffer from "burnout." Burnout - neglecting your own needs to the point where you become so fatigued, malnourished, or emotionally overburdened that you can no longer continue caregiving – is harmful not only to yourself, but to your loved ones as well.

There are a variety of ways to provide some quick relief for stress. Sometimes just taking a deep breath or "counting to ten" will relieve the immediate stress you are experiencing and allow you to continue responding to a stressful

situation more calmly and effectively. Mild exercise – a walk, swim, yoga exercises – can also quickly reduce your stress level. Sometimes, a personal "affirmation" (a statement or personal reminder of a positive personal characteristic or coping capacity you have), such as the famous Alcoholics Anonymous reminder "One day at a time," is sufficient to reduce stress and remind yourself that you can make it through this day despite its difficulties and challenges. Get someone to give you a break and take some time off for something you love to do – a movie; a relaxing long, hot bath; reading a book; having your hair done.

If you feel that constant stress has brought you to the point of burnout, professional help may be necessary, for your sake as well as the sake of those you love. If you suspect that caregiving is affecting your physical or mental health, see your physician or other health professional who can suggest ways to help you cope with the stress you're experiencing. Local caregiver support groups can also be very helpful, as well as caregiver respite programs which can relieve you of your caregiving activities for short periods of time.

Whatever your method of choice for reducing stress, the most important thing to remember is that taking care of yourself is just as important as taking care of those you love.

## *Balancing Work and Caregiving*

What would you do if you were forced to choose between your job and your family? Every day caregivers are asked to do just that, often facing difficult choices about whom or what to sacrifice for the sake of the other.

Sixty-four percent of caregivers work full or part-time. There is no magic formula for what is most important, or what will work for you in making that decision, but the advice from working caregivers is that it is almost impossible to "have it all." The reality is that you must be prepared to face the necessary tradeoffs of balancing sometimes competing demands on your physical, emotional, and sometimes financial resources.

Decide what's most important to you – determine your life goals. Then look at what achieving those goals will require. The experts recommend that you be absolutely honest with yourself about what it will take to accomplish your goals. Next, talk about this with your spouse, family, and the person you're providing care for. Understanding the work demands you face is an important part for all of them. Next, discuss your situation with your boss (if you have your own company, that may mean yourself!) Letting your supervisor know that you have caregiving demands is the first step in creating some workable strategies for compromise on everyone's part. It's often easier if you can develop some creative alternatives that will allow you to make the best choices – for example, is there some way to work

effectively with a more flexible work schedule? Does the company provide any assistance or benefits for working caregivers? The Family and Medical Leave Act provides for specific periods of unpaid leave for caregiving for ill parents or children and can be used for short-term caregiving emergencies. For most employed caregivers, however, the typical long-term nature of caregiving responsibilities requires longer term solutions. Also, check with your human resources person or the employee assistance program to see what benefits your company offers.

Remember you are not alone in this challenge, many caregivers face the difficult choices of family and career. A perspective from others is available in several books: "Balancing Act: How Managers Can Integrate Successful Careers and Fulfilling Personal Lives," by Joan Kofodimos (Jossey-Bass, 1993) 800-956 7739; and "Body and Soul," by Anita Roddick (Crown Publ., 1991) 800-726-0600.

Another good resource is the Families and Work Institute, 330 Seventh Ave. New York, NY 10001, 212-465-2044 [www.familiesandwork.org](http://www.familiesandwork.org) for a variety of reports, guides, etc. on balancing your life, career, and caregiving.

## *Options For Senior Living*

### *Aging in Your Own Home*

The alternatives for senior living are not limited to living at home or in a nursing home. Rather they incorporate



what is called “the continuum of care.” This continuum encompasses totally independent living at home, through assisted living in a variety of retirement residential settings, to the most intense nursing-related care provided in nursing homes. Today, between in-home services and less intense care facilities such as assisted living facilities, caregivers and care recipients have a wider variety of appropriate choices for care than ever before.

Research shows that staying at home is the living arrangement clearly preferred by an increasing number of today’s older men and women. A recent survey by AARP, for example, found that 85% of older respondents prefer to remain in their own homes if they need care. Over the past two decades the support for aging in place in one’s own home have improved dramatically. Consider two sets of factors and consumer decisions as you evaluate the desirability and feasibility of providing care for your elder in her or his own home (or in yours). The first factors concern physical changes in the home itself – home modifications, assistive and supportive devices that can be purchased or rented, safety, and emergency response systems. The second set of factors and decisions to consider concerns services. “Home care” is the general phrase describing bringing such help as nurses, companions, transportation providers, and home care and personal care aides into your elder’s home. These are discussed in the following section.

\* Assistive Devices for the home are probably your first consideration. Mobility devices are the more obvious first kinds of assistance that a frail older person needs. Everyone is familiar with canes, walkers, and wheelchairs – although even these come with a variety of options and prices. Each room in your relative’s apartment can be re-fitted or re-furnished with products and devices to increase safety, convenience and independence – from rubber-like non-slip doorknobs, to reachers to pick objects up from the floor without having to bend down, to pneumatic living room chairs that automatically rise to help an older person get out of the chair.

The federal government’s National Institute on Disability and Rehabilitation Research has developed an enormous database of assistive devices and rehabilitative products. The ABLEDATA Database includes listings of over 17,000 products currently available from 3,000 different manufacturers and distributors. Call 1-800-227-0216 (8455 Colesville Rd., Silver Spring, MD 20910 [www.abledata.com](http://www.abledata.com)) to get on the Institute’s mailing list and to get access to the database. Each entry includes a description of the product, its retail price (and the date the price was identified), the manufacturer’s name (and address and telephone number), availability (manufacturer only or also local distributors), and any “special” comments such as “assembly required” or “Medicare reimbursable.”

\* Home Modification. Declines in physical strength, vision, and hearing as well as diseases such as arthritis can often be dealt with by modifications in the home. Some are more easy to accomplish than others; some are costly. All such changes should be discussed with the older person who will use them and with others who may in the future be involved personally or financially in caregiving. Check with an occupational therapist for help in identifying which modifications are needed.

ADL (Activities of Daily Living) studies show that bathing, toileting, and eating are the activities that most clearly signal declines in an older person's capacity to live independently. Traditional bath tubs can be replaced by tubs with lower sides or fitted with grab bars. Doorknobs, faucets, and cabinet handles can be replaced with larger lever-type handles, rather than round knobs, for easier and safer use by elderly hands. Household lighting can be made brighter (but not glaring) throughout the home, sometimes simply by increasing light bulb wattage or by installing different kinds of lamps and lighting. Where mobility has declined, ramps and even elevators or banister-chair lifts could be installed, among other things.

A comprehensive and readable source of very practical information on this range of home modifications is available in The Do-able Renewable Home by AARP. The book is available from AARP or from the website of the

Andrus Gerontology Center of the University of Southern California:  
[www.usc.edu/dept/gero/hmap/library/drhome](http://www.usc.edu/dept/gero/hmap/library/drhome).

\* A Personal Emergency Response System (PERS) is an electronic device connected to the home telephone that automatically summons help in an emergency. A PERS consists of a small radio transmitter usually worn as a necklace or bracelet so the user can press it wherever he or she is (in bed, on the floor, in the bathroom) when he or she falls or has an emergency. When the radio transmitter is activated, it sends a signal to a telephone response center, even if the phone itself is off the hook. The response center can be a local PERS system, the local hospital, or 911.

Dealers ranging from small companies to the regional phone companies offer both the PERS equipment and the response center response services. Hospitals and local aging or social services agencies in your community may act as "middlemen" in linking you to preferred dealers. Monthly rental including both the in-home equipment and the response center service can range from \$15 to \$50 per month. The cost is generally not Medicare reimbursable, but some private insurance may pay for all or part of the system.

The best place to start your investigation is the comprehensive report prepared by the Federal Trade Commission called simply "Personal Emergency Response Systems." Write to



the FTC Office of Consumer and Business Education (Bureau of Consumer Protection), 600 Pennsylvania Ave, NW, Washington, D.C. 20580; call them 202-326-3650, or read the report on [www.ftc.gov/bcp/online/pubs/services/pers.htm](http://www.ftc.gov/bcp/online/pubs/services/pers.htm).

In addition, AARP has prepared a consumer guide to PERS systems that summarizes the characteristics of twenty different systems. Request [Product Report: PERS](#) (Report #D12905).

\* Home Safety. When you and your elder have concluded that living at home is both desirable and feasible, it is essential that you do a comprehensive home safety evaluation. Evaluate your home for slippery floors, glaring lighting, sharp table corners, unbalanced tables, or exposed electric cords. Aside from the home itself, the older resident's health and mobility add another layer of safety planning concerns. The spacing of furniture, doorways, and appliances need to be examined, along with the safe location and spacing of tables, chairs, cabinets and appliances. Use the five basic Activities of Daily Living as another way of looking for "safety violations" – can your elder eat, bathe, go to the bathroom, get dressed, and move from his or her bed to a chair safely?

Some area agencies on aging, county health programs, hospitals, HMOs, and senior centers provide outreach in-home safety evaluation services. They may be called Falls Prevention

programs or simply home safety programs. Books, pamphlets, and other easy to use publications are available available from these community agencies or from AARP.

The Agenet website, [www.agenet.com](http://www.agenet.com), offers a comprehensive home safety checklist for use by caregivers and elders to assess possible hazards within the home. The 60 very specific questions focus your attention on specific parts of the home on a room by room basis.

AARP's Connections for Independent Living is a continually updated local community program that helps older people remain independent through the assistance of AARP members as volunteers. Check the AARP website for dates and addresses where local home safety workshops and information exchanges are currently scheduled: [www.aarp.org/programs/connect/home.html](http://www.aarp.org/programs/connect/home.html).

### *Bringing Aging Services into the Home*

Finding and arranging for home care, which typically focuses on Activities of Daily Living rather than health and medical services, and then monitoring the care is an essential service for an elder remaining at home. Most communities have services available to help older people remain independent or cared for at home (in their own home or the home of a relative). The National Institute on Aging identifies the following services: homemaker/

home health aide services, home-delivered meals, transportation and escort services, household workers, a Friendly Visitors Program, adult day care programs, respite care for caregivers, and emergency medical systems. Some of these support services and others are funded by state and county programs or offered by church or volunteer groups. Eligibility criteria and cost vary greatly by location, and you will want to function as your older relative's advocate in identifying and arranging services from the state or local agencies.

Home care is emerging as a specialized service industry with much variation in the scope of services, quality of service and cost. Home care workers includes visiting nurses, physical therapists, occupational therapists, and home health aides, as well as non-medical personnel who serve as companions, homemakers, personal care attendants, and escort/transportation providers.

In addition to the fundamental questions of quality, availability, and affordability of the service, home care requires the caregiver to be an advocate for the older person's services:

- \* Who will find, screen, and recruit the home care service providers?
- \* Who is responsible for paying the home care bills? If it is to be the older person him/herself, will the medical problems that initiated the reason for the care prevent effective supervision of the home care providers?

\* Will there be just one provider or will it take several different services – e.g., meals, housekeeping, transportation, everyday assistance inside the apartment, taking medications, physical therapy? Who will coordinate these several services?

\* If a home care worker is delayed or doesn't show up, what is the back-up system? Who will monitor the daily activities of the home care workers, and who is responsible for finding the substitutes?

If staying in his or her own home environment is your elder's decision, then home care may be available, along with assistance in arranging for it. Several national temporary employment companies have divisions that specialize in home care, and hospital discharge planners or geriatric care managers can also be particularly helpful in making home-care arrangements. There are also many community-based local providers offering in-home services, such as "Meals on Wheels" which provides low-cost nutritious meals for those who cannot get out to shop or dine. Try the Eldercare Locator (800-677-1116) or your local telephone book "Blue Pages" for the services.

#### FURTHER INFORMATION:

Ada Romaine-Davis, Jennifer Boodas, and Ayelife Lenihan (editors), Encyclopedia of Home Care for the Elderly. Greenwood Publishing Group (1995).

D. Helen Susik, Hiring Home Caregivers—The Family Guide to

In-Home Eldercare. American Source Books, San Luis Obispo, CA (1995).

The National Association for Home Care (NAHC) is a trade association that represents 6,000 home care agencies, hospices, and home care aide organizations. NAHC provides consumers with information on how to define their need for home care assistance, how to judge provider qualifications, how to locate home care agencies in the community, and how to finance home care. NAHC, 228 Seventh Street, SE, Washington, DC 20003, (202) 547-7424. [www.nahc.org](http://www.nahc.org) and [www.homecareuniversity.org](http://www.homecareuniversity.org).

When home care needs extend beyond Activities of Daily Living to require additional medical and pharmaceutical services, a visiting nurse may be necessary. Visiting Nurse Associations (VNA), with 513 locations in 40 states, are community-based and community-supported nonprofit home health care providers. In addition to general information about services, the VNA website offers a map-based locator service: 11 Beacon Street, Suite 910, Boston, MA 02108. Tel: 617-523-4042. [www.vnaa.org](http://www.vnaa.org).

### *Adult Day Services*

A relatively new kind of care as an extension of home care, known as Adult Day Care (or Adult Day Services), is becoming common. In this kind of care, your elder attends a community facility during the day, where an array of social, recreational, and at some sites

health services are available. The older person who lives at home can also have the experience of meals, recreation, some therapy and medical services in an organized and supervised environment. Simultaneously, the adult day center offers a reprieve to the caregiver. The time off offered by the adult day center may well spell the difference between continued at-home residence and a move to a nursing home or other senior living accommodation.

Many adult day care centers include a nurse or other health professional who will perform various screening services as needed. Some adult day centers are specially designed to work with Alzheimer's patients.

Consumers can locate adult day services in their community a number of ways, including:

- The federal government's Eldercare Locator (800-677-1116)
- The local Yellow Pages, under "adult day care," "aging services," "senior services," etc.
- Through the Information & Referral desk at your local Area Agency on Aging (call 800-677-1116) or look in the Blue Pages section of the phone book to find the local area agency. Local senior centers can also recommend adult daycenters.
- The National Adult Day Services Association (NADSA) is the national organization for the approximately 4,000 local adult day service centers

throughout the US; it also helps consumers locate appropriate services. NADSA/NCOA, 409 Third Street, SW, Washington, DC 20024. 800-424-9046. [www.ncoa.org/nadsa](http://www.ncoa.org/nadsa).

## *Assisted Living*

There are two basic models for Assisted Living residence and assistive services: the Rental Model (which follows a hotel or apartment way of doing business) and the Condo Model. The rental model operates on a month-to-month basis, often with a yearly lease. In the condo model, you purchase the residence, usually by making a substantial down payment (as little as \$50,000 or as much as \$350,000) and then have a monthly maintenance fee. There are also variations in the amount of assistance you get for the monthly fee. Assisted living usually includes meals in a dining room setting, house-keeping services, and a range of health and personal assistance depending on the older person's needs.

If you and your relative are considering assisted living, consumer advocates suggest the following considerations:

- \* For what time period does the facility guarantee care?
- \* Is it certified by the Continuing Care Accreditation Committee and a state or local agency?
- \* Is there special care for Alzheimer's patients?
- \* What specific services are supplied under the categories of grooming,

bathing, eating, and transportation?

- \* Does a resident have to be ambulatory or are walkers and wheelchairs allowed?
- \* Are there additional costs if meals must be delivered to the apartment?

### FURTHER INFORMATION:

An excellent place to start your search is with [Assisted Living Housing for the Elderly – Design Innovations from the United States and Europe](#) (1994) by Victor Regnier.

The American Association for Homes and Services for the Aging (AAHSA) is the association of non-profit senior housing facilities, including nursing homes, CCRCs, and assisted living residences. AAHSA offers a directory of its member facilities to help consumers find appropriate residences, and distributes a series of booklets on how to evaluate and choose a nursing home, a CCRC, an assisted living place, or home care provider. AAHSA, 901 E St. NW, Suite 500, Washington, DC 20004-2011. 202-783-2242. [www.aahsa.org](http://www.aahsa.org).

The American Health Care Association (AHCA) is a membership association of 12,000 senior housing facilities including nursing homes, CCRCs, and assisted living facilities, most of which are in the proprietary for-profit sector, but includes some non-profits as well. AHCA provides substantial consumer information: 1201 L Street, NW, Washington, DC 20005, 202-842-4444. [www.ahca.org](http://www.ahca.org).

The Assisted Living Federation of America (ALFA), the professional association whose members are solely assisted living facilities, provides information and criteria useful in choosing the right facility. In addition, the organization's website offers a state by state listing of facilities, searchable by county and city; each entry includes a street map of the facility's location. 10300 Eaton Place, Suite 400, Fairfax, VA 22030. 703-691-8100. [www.alfa.org](http://www.alfa.org).

### *Nursing Homes vs. Assisted Living, and other Housing/ Care Options*

Because Nursing Homes – as a general category – are used both for the post-hospital acute care and short-term rehabilitative care of older patients, the confusion between Medicare and Medicaid as payment for “nursing care” persists despite thirty years of public education. Medicare does NOT pay for chronic nursing home care. The fact that Medicare does pay for both an older person's hip surgery and his/her short-term rehabilitative services required thereafter (which may be provided at a nursing home) creates confusion.

The confusion over the two kinds of nursing home stays further complicates public understanding of Medicare versus Medicaid. Since Medicare pays only for short-term post-hospitalization recuperation in skilled nursing facilities (nonetheless labeled as “Nursing Home” stays), the public continues to perceive

incorrectly that Medicare pays for chronic nursing home utilization. Many people also believe that Medicare pays for long term chronic care services in the home. It does not.

Over the past decade, with increasing longevity and therefore an increasing need for chronic longer-term care, Assisted Living has grown dramatically. As described in the previous section, this relatively new kind of senior housing is generally defined as independent living, but with various kinds (and levels) of assistance, for older persons who do not need the daily nursing care. But caution is needed. Assisted living can range from large corporate chains to “mom and pop” businesses in which a few rooms in an old large house are made available on a room-and-board basis with relatively little assistance.

Continuing Care Retirement Communities (CCRCs) offer independent living, assisted living (with some assistance in everyday activities), and a nursing home all on the same campus, so that the older person can receive more intensive care as he or she requires it.

### *Finding the Right Senior Housing*

When you are evaluating and selecting a senior housing facility with a relative or friend, you should visit and compare several facilities, according to National Citizens' Coalition for Nursing Home Reform. Visit each one several times, at different times of the day, and use all of

your common senses, including sight and smell, to judge factors on whether residents are properly dressed, the food is appetizing, and the staff responds to patients' calls for assistance.

To summarize:

- \* Residential care facilities provide room and board and may offer social, recreational, and spiritual programs.
- \* Continuing care retirement communities (CCRC) start with independent living and progress to more intensive care services, including room and board, personal and health care, and social activities.
- \* Assisted living facilities include retirement homes and board and care homes. Services differ from location to location but usually include meals, recreation, security, and assistance with Activities of Daily Living as noted earlier, and medication management.
- \* Skilled nursing facilities offer services for those who need 24-hour medical care and supervision. Emphasis is on medical care with rehabilitative therapy to maintain or improve abilities.

Call the Eldercare Locator (800-677-1116) for local resources in each of these areas.

The National Citizens' Coalition for Nursing Home Reform helps local organizations work for nursing home reform and improvements in long-term care. To learn more about the Coalition and for a list of consumer publications:

202-332-2275 1424 16th St., Ste. 202,  
Washington, DC 20036 [www.nccnhr.org](http://www.nccnhr.org).

The Nursing Home Information Service is an information and referral center for consumers of long-term care and their families, friends, and advocates, including information on nursing homes and alternative community and health services. Write to the National Council of Senior Citizens, Nursing Home Information Service, National Senior Education and Research Center, Inc., 8403 Colesville Rd., Ste. 1200, Silver Spring, MD 20910 (301-578-8800) [www.ncscinc.org](http://www.ncscinc.org).

AARP can provide general information on long-term care for consumers. For a list of their publications, write to the AARP Health Advocacy Services, 601 E St., NW., Washington, DC 20049 (202-434-2277). Their website, [www.aarp.org](http://www.aarp.org), also provides useful introductions to the issue.

AAHSA, in conjunction with AARP, has information about continuing care retirement communities. Write to the AARP/Housing Activities (at the address above).

### *Reverse Mortgages*

For older people who have not purchased long-term care insurance and who are between the extremes of self-insuring wealth and Medicaid eligibility, an alternative source of financing long-term care may be the equity in the older person's home. Home equity is the single largest source of wealth of older people in the United

States today. A Reverse Mortgage, a loan given by a bank or other lending institution using the paid-up value of the home as collateral, might be used to pay for medical and home care bills.

FURTHER INFORMATION:

Reverse mortgages are offered by some (but not all) retail banks, S&Ls, and other banking organizations. First check with your local bank to see if they offer reverse mortgages, and with what terms and rules.

Look for Your New Retirement Nest Egg: A Consumer Guide to the New Reverse Mortgages (1996) by the National Center for Home Equity Conversion. This book describes in great detail the variations in reverse mortgage plans sanctioned by recent federal law, how to calculate your costs

and returns, and a detailed appendix on where to find lenders in your state that offer reverse mortgages. 7373 147th Street West, Apple Valley, MN 55124, 612-953-4474. [www.reverse.org](http://www.reverse.org).

AARP administers its AARP Home Equity Information Center as a focal point for consumer-directed information on reverse mortgages. The Center provides a range of books, pamphlets, and videotapes on such subjects as federally-insured mortgages, cost and eligibility issues, different ways of receiving the cash from home equity, and how to select a reverse mortgage counselor and lender. Contact the Home Equity Information Center at the AARP Foundation, 601 E Street NW, Washington, DC 20049. The website address, part of the AARP's Webplace, is [www.aarp.org/hecc](http://www.aarp.org/hecc).



## Part Two—Planning for Your Own Long-Term Care

You've learned a great deal about caregiving in Part One. This second part of the guide was developed to help caregivers and prospective caregivers start planning for their own long-term care. It includes descriptions of some of the important issues and lists of resources for more information.

### *General Health and Finance*

#### *Medicare vs. Social Security Eligibility*

While most people know that Medicare is the national health insurance for people over 65 in the United States, many Americans do not realize that Medicare eligibility does not begin until age 65, even if you choose early Social Security retirement at age 62 or 63. A recent national survey found that almost half of American adults falsely believe that you qualify for Medicare whenever you start to receive Social Security.

Similarly, less than two-thirds of Americans correctly know that even if you have a private pension from an employer, your employer is not required to provide paid or subsidized retiree health insurance. In planning for yourself, be sure to check with the appropriate employer personnel office or the employee assistance program, read the fine print in retirement benefits and health insurance brochures, and ask if any retiree health insurance that is offered can change or is likely to change in cost and coverage in the next few years.

As you plan for the future payment of health costs, be sure you know where the necessary health insurance will come from – and how it will be paid for. This is especially true if you are considering early retirement and, like most people, the necessary health insurance is connected to employment.

HCFA (the U.S. Health Care Financing Administration), the department that administers Medicare, provides three sources of up-to-date information not only on Medicare itself, but guides on purchasing private supplemental health insurance: 1-800-MEDICARE. The 1999 Guide to Health Insurance for People with Medicare. [www.medicare.gov](http://www.medicare.gov).

If you want or need to purchase health insurance on your own, consider the following:

Ask your former employer about your rights under the Comprehensive Omnibus Budget Reconciliation Act (COBRA) legislation, which often allows former employees to purchase the same health insurance plan that they had when they were working (the number of months varies depending on the family and employment circumstances.)

Group health insurance is almost always less expensive than individual insurance, so check with all the groups, teams, social clubs, professional, fraternal, and hobby organizations you or your family members belong to, because many offer group health insurance as a benefit of membership.



Also, keep in mind that Medicare and Social Security have waiting periods involved in qualifying for benefits, so apply for these benefits several months before you plan to retire.

## *Disability Insurance vs. Life Insurance*

Most employees have some kind of disability insurance through their employment primarily to replace part of their income if they are no longer able to work. For middle-agers, disability income insurance is at least as important as life insurance because a middle-ager is more likely to become disabled than die. Be sure to understand what kind and amount of disability insurance you have, how it works, and how much it would cost to purchase more.

In addition to its basic purpose in providing retirement income, Social Security is also a basic disability income insurance policy whose benefits are available to workers at any age, not just 62 or 65, depending on the nature of the disability. However, Social Security disability benefits are not easy to qualify for since disability means you are so severely impaired, physically or mentally, that you cannot perform any substitute gainful work. The impairment must be expected to last at least 12 months or to result in early death. To learn more about Social Security Disability Insurance, obtain a copy of the most current Social Security

Handbook from the: Social Security Administration, Office of Public Inquiries 6401 Security Blvd., Baltimore, MD 21235(800-772-1213). Also look at their website at [www.ssa.gov](http://www.ssa.gov). Remember that disability benefits may have a long waiting period, so apply early.

Check with your employer to learn what kind of disability income insurance you have through your job; in many states this is required insurance. You should get answers to these questions as part of your general retirement planning, – before the benefit might be needed.

## *Life Insurance*

Most families need some life insurance. You should consider the kind and amount in terms of the basic purpose life insurance is intended to serve. In most cases, life insurance is intended to provide cash to replace the income a family loses due to the death of the person earning the income. In the case of the death of a non-working spouse, the cost of providing child care may also need to be covered. Consequently, in most younger households, both husband and wife should consider having life insurance.

When you shop for insurance, there are four key ideas to keep in mind –

- (1) Seriously consider whether you really need life insurance, and if so, how much.
- (2) Consider which type of insurance is

right for you: term life insurance, whole life, or universal life insurance.

3) Understand the options, costs, and benefits that are part of the term life insurance "product."

(4) Shop around, look at price, consider company quality as well as product features.

*Consumer Reports*, July 1998 (available at most libraries), offers an excellent overview of the differences between term life insurance and whole or universal life insurance. The article also provides a calculator process by which you can estimate your own need for life insurance. This decision should be made in the context of your overall financial planning; consult with financial professionals, if desired.

Note: the following are examples of insurance information services, not recommendations:

[www.termcomparison.com](http://www.termcomparison.com)

Or: 1-888-825-8762

[www.quotesmith.com](http://www.quotesmith.com)

Or: 1-800-556-9393

[www.insweb.com/ins101](http://www.insweb.com/ins101)

[www.quicken.com/insurance](http://www.quicken.com/insurance) includes an elaborate life insurance section, including definitions, discussion of how life insurance fits into financial planning, and access to costs and quotes.

## *Basic Financial Planning*

### *Financial Planning Stages to Know and Understand*

The title of this section is financial planning and not "retirement planning," for two reasons. First, the line between work and retirement is not as clear-cut as it used to be: an increasing number of "young-old" Americans now choose partial, phased, or delayed retirement. Second, there are several different ages at which you can begin to get various pension and retirement benefits, and you don't have to stop working to get the money. Therefore, your decision about whether to work or retire should be made in the context of the larger issue of your financial planning for your later years.

\* Social Security. The "traditional" retirement age is 65; this is generally the age at which you get "full benefits". You can retire and get Social Security at any time between 62 and 65, but your monthly benefit will be reduced based on the number of months prior to age 65, and this will be a lifelong reduction. You also have to make a formal application for Social Security payments at least 60 days before you need to take them. Documents such as proof of birth, citizenship, or marriage are needed.

\* Qualified Retirement Plans. In some (such as IRAs or 401[k] plans) you can

begin to withdraw funds at age 59 1/2, even if you don't stop working. But note that (a) you are not required to withdraw funds at this age, and (b) if you withdraw funds earlier than age 59 1/2, you will incur a 10% tax penalty in addition to any income taxes you may owe. Also, if you are still working at age 59 1/2, withdrawals will depend on plan provisions. You must begin taking a "minimum withdrawal" from IRA accounts no later than April 1st following the calendar year in which you reach 70 1/2, even if you continue to work. If withdrawals are not started by 70 1/2 you will incur a penalty.

#### FURTHER INFORMATION:

Call the Social Security Administration at 1-800-772-1213 to find out more about the age and eligibility rules for early and "normal" (currently age 65) retirement procedures. Its website, [www.ssa.gov](http://www.ssa.gov), provides an automated local office locator. When you type in your zip code, the website returns the address, the hours the office is open, a street map of the location, and written driving instructions.

To find out what your Social Security retirement benefit will be when you hope to retire, request your Personal Earnings and Benefits Estimate Statement – your "PEBES" – from Social Security; ask for a PEBES request form (#SSA-7004) by calling your local SSA office, or from the SSA website. Obtain a copy of either or both of the following free SSA booklets– When planning for your future retirement: Social Security Retirement Benefits

(#05-10035, February 1999). To better understand the benefits and procedures once you have started receiving Social Security benefits: What You Need to Know When You Get Retirement or Survivors Benefits (#05-10077, January 1999).

### *Defined Benefit vs. Defined Contribution Pensions*

There are two basic types of pension plans: Defined Benefit plans and Defined Contribution plans.

A defined benefit pension is the "traditional" employer-provided or union-provided pension: what is defined is the dollar amount of the benefit you get when you retire (based on such things as years of employment and amount of regular income). The financial risk is shouldered by the pension plan which is obligated to make sure that the cash is available to pay the promised benefit.

In the defined contribution pension, the only amount defined in advance is the amount contributed into the pension, either by you or your employer (or a combination of both). There is no guarantee of how much cash these Keogh, IRA, or 401(k) accounts will be worth years later when you retire. And while employers typically offer investment advice and a variety of investment options, the financial risk is on your shoulders, because only the amount of the contribution is guaranteed. If your pension is a defined

contribution plan, then there is less regulation to protect you, and you have to know more about your own financial and investment responsibilities.

#### FURTHER INFORMATION:

Your local library should have the following useful books that discuss pensions:

James E. Birren (editor), Encyclopedia of Gerontology: Age, Aging, and the Aged. Academic Press (1996).

George L. Maddox (editor), Encyclopedia of Aging: A Comprehensive Resource in Gerontology and Geriatrics (2nd Ed.). Springer Publishing Co. (1996).

Lois A. Vitt and Jurg K. Siegenthaler (editors), Encyclopedia of Financial Gerontology. Greenwood Publishing (1996).

If you have questions about your pension rights, or want to report a pension rights violation, contact the U.S. Department of Labor's Pension and Welfare Benefits Administration (PWBA), 200 Constitution Ave., NW Washington, DC 20210. Their general publications request number is 800-998-7542, and their Technical Assistance and Inquiries number is 202-219-8776. In addition to its national offices in Washington, DC, the PWBA has 15 Regional and District Offices around the country. Call the main 800 number to find your closest regional office or visit their website at [www.dol.gov/dol/pwba/public/contacts](http://www.dol.gov/dol/pwba/public/contacts).

The most immediate and relevant source of pension and pension rights information is your employer. Make an appointment with the Personnel, Benefits, Human Resources department or employee assistance program. Find out how your employer's pension system works not only in terms of contributing and investing money, but the rules and regulations about receiving the funds in the form of a pension.

### *Pension Rights of Spouses and Surviving Spouses*

The 1974 ERISA pension law requires that husband and wife at least discuss what the employee will do when he (or she) elects to receive his (or her) pension. For example, a retired husband can choose to receive a reduced amount, say 80% of his pension for the rest of his life instead of 100%, so that his widow will receive a specified amount until she dies. Each has to sign an ERISA form saying that they have discussed the options.

The strategy and calculations are based on such things as his and her health status, how much income they estimate they will need and the full profile of where that income will come from.

### *Retirement, Early Retirement, and Health Insurance*

In addition to all the financial calculations you do in planning for

retirement, don't forget about the availability and the cost of health insurance. Many working-age individuals get their health insurance through their workplace. So, as you get closer to retirement, be sure that you know where your health insurance will come from. Remember that a person is not eligible for Medicare until age 65 – which is separate from other Social Security retirement ages and benefits.

#### FURTHER INFORMATION:

To better understand the protections which ERISA gives to women and surviving spouses, contact the Department of Labor to request a copy of their "Know and Do" booklet. The Pension and Welfare Benefits Administration (PWBA) of the Department of Labor, mentioned earlier, is the contact place for this publication: 200 Constitution Ave., NW Washington, DC 20210. 800-998-7542.

The non-governmental Pension Rights Center in Washington, DC, operates a Legal Outreach Program to protect the pension rights of workers, retirees, and their families. 1140 19th St., NW, Ste. 602, Washington, DC 20036 (202) 296-3776.

The Older Women's League is especially concerned with the pension rights of spouses and widows: 666 Eleventh Street, NW, Suite 700, Washington, DC 20001. OWL has local and state chapters throughout the country; to locate a chapter near you call: 1-800-825-3695.

The National Center on Women and Aging at Brandeis University serves as a clearinghouse of current information on financial issues for women and aging more generally. National Center on Women and Aging, Heller School, MS035, Brandeis University, Waltham, MA 02454-9110. 800-929-1995  
[www.brandeis.edu/heller/national/ind.html](http://www.brandeis.edu/heller/national/ind.html).

### *Saving and Investing for "Retirement"*

Defined contribution pension plans and self-directed Individual Retirement Accounts put more financial and investment responsibility on the shoulders of working men and women than used to be the case. Because of the dramatic increase in the kinds and sources of investment and savings advice to help you, start with the following basic principles as an introductory set of suggestions and cautions.

If you're fairly new to pensions and investments, a good place to start is with the series of books available in many bookstores these days, the "Dummies" Books. Personal Finance for Dummies, for example, makes the important point that personal finance is NOT simply a question of investments, but involves a broader range of information including saving, budgeting, mortgages, insurance, and records-keeping. After this introductory volume, you may want to read Investing for Dummies and Mutual Funds for Dummies.

Some tips for saving and “investing” in retirement:

\_ If you have a defined contribution pension such as a 401 (k) plan, and if your employer matches all or part of your contribution, then be sure you contribute the maximum amount allowed.

- Pension rules and eligibility have changed dramatically over the past few years. Even if you and/or your spouse have a pension plan at work, you may also be eligible to open a traditional IRA (although you may not be able to deduct your contributions) or a Roth IRA.

#### FOR MORE INFORMATION

The Internet offers a virtual cornucopia of educational material, financial opinions and, planning tools. Your first visits should be to one or more of the several mass media “household names” that have created excellent (and free) financial websites (e.g., [www.cnbc.com](http://www.cnbc.com), [www.asec.org](http://www.asec.org), [www.cnnfn.com](http://www.cnnfn.com), and [www.washingtonpost.com](http://www.washingtonpost.com)). Many financial services and mutual fund companies also offer valuable financial planning and educational websites. Also, you may want to check general “financial data” websites (e.g., [www.quicken.com](http://www.quicken.com) and [www.bloomberg.com](http://www.bloomberg.com)) that provide historical as well as current historical mutual fund and stock price information and graphs, company and fund profiles, investment strategies, daily financial news, and even free personal portfolio management tools.

The finance section of USA Today's website, [www.usatoday.com](http://www.usatoday.com), includes no fewer than 100 different financial calculators pertaining to budgeting, insurance, mortgages, stocks and mutual funds purchasing – and retirement planning. A similar selection is available from Kiplinger's personal finance magazine at [www.kiplingers.com](http://www.kiplingers.com).

### *Long-Term Care*

#### *Insurance: The Basics*

Although long-term care insurance has been around for about twenty-five years or so, the nature of the policies, the kinds of features they include, and their costs have changed and evolved dramatically. It is appropriate to consider this form of financial protection, but there are many questions and issues that you should explore. Keep in mind that this is a long-term investment. That is, you are purchasing something now that may not pay a benefit for 20 or even 30 years. Or, like fire insurance on your home, maybe it won't pay off at all if you die without needing long-term care.

Here are some basic questions to ask about any long-term care (LTC) insurance policy you are considering:

- What kinds of long-term care services are covered by the policy? It should cover home care as well as nursing home care.
- How does the policy typically pay a benefit? Does it provide a specific, fixed



number of dollars per day, e.g., \$125 per day, or does it provide a percentage of the actual cost charged by the nursing home (or other long-term care service)?

- Whether dollars per day or percentage, is there a difference in the nursing home benefit compared to the home care benefit? You will have maximum flexibility if the policy pays, for example, \$150/day for nursing home care or \$150/day for home care services.

- What are the "triggers" for receiving the long-term care benefits from the policy? Will a signed statement from your doctor be sufficient or does it require certification from the insurance company's medical staff? Will two non-medical Activities of Daily Living needs be sufficient to trigger payment of benefits? Is the number or combination of ADLs such that triggering is more than likely?

- What are the deductibles, co-payments, and waiting periods in the policy? Most LTC policies have a 30-day to 90-day waiting period. Like the \$500 deductible in automobile collision insurance, if you are willing to pay for the first month or two of care, the policy premiums will be lower.

- How will the long-term care insurance "connect" or "integrate" with Medicare and other health insurance you may have? Are there elements of the nursing home care or home care costs that will be paid by other insurance? Conversely, does the long-term care policy assume that other sources will pay for certain

services (e.g., medicines or physical therapy)?

- What about inflation? Does the policy include, or offer, protection against the rising costs of nursing home care? How much does the "inflation protection rider" to the policy cost? Is the inflation protection automatically renewed each year?

- Are there rebates and returns? What happens if you decide not to continue with the policy? Is there a short period (e.g., 30 days) during which you can change your mind and cancel the contract? What happens if you decide you don't want the policy after several years; is there any rebate? Is there any cash value build-up in the policy that you can borrow or receive? Can the policy be converted to other kinds of long-term care insurance or other kinds of health insurance?

Ultimately, the important thing to remember is: generally, the younger you are at the time of purchase, the lower the premium. Willingness to take risk is a large part of the personal and family decision on long-term care insurance. Are you willing to risk that you will not have substantial long-term care expenses in the next ten years? And are you willing to risk the possibility of not being able to qualify for long-term care insurance ten years from now?

FOR MORE INFORMATION—  
Information can be found in the October 1997 Consumer Reports Special Report on long-term care insurance,

"How Will You Pay for Your Old Age?" (available in most libraries.) The comprehensive 13-page article describes the basic elements of an LTC insurance policy, demonstrates how you can judge the merits of a policy, discusses the "strategy" of private insurance versus Medicaid spend-down requirements, indicates how you should prepare to talk to an insurance agent, and provides company-specific descriptions and quality ratings.

One of the most comprehensive sources for consumer-accurate and consumer-friendly information on long-term care insurance is the non-profit United Seniors Health Cooperative, 409 Third St., SW, 2nd Fl., Washington, DC 20024; (202) 479-6692. USHC has produced Long-term Care Planning: A Dollar and Sense Guide (about \$18). [www.ushc-online.org](http://www.ushc-online.org).

### *Harvesting Your Retirement Investments*

"Harvesting" here simply refers to actions you can take or should avoid taking typically before retirement, when you are in your forties, fifties, and sixties, in order to get the most out of your retirement-oriented investments.

There are several federal tax rules regarding when you may withdraw money from your retirement accounts and when you must withdraw funds from those accounts. For example, you may begin to withdraw money from your IRA at age 59½ but you don't have to (taking money out of a

retirement account before 59½ will cost a 10% penalty in addition to any income taxes you owe). But because these funds were tax deferred for retirement income purposes, you may have to start withdrawing minimum amounts at least by age 70½ even if you don't really need the money, and even if you are still working.

Having a strategy for making these withdrawals also involves understanding the required amounts of the "minimum distributions," how to calculate your longevity at the time you begin the withdrawals, whom you have named as a beneficiary and how old that person is, and personal choices concerning how quickly or slowly you want to withdraw the money from the accounts.

Information on topics related to "harvesting" regularly appear in the following places:

Most local newspapers include a weekly column on personal finance. Watch for articles on retirement planning that specifically discuss ways to withdraw money from retirement accounts.

The second section of the Wall Street Journal regularly includes personal finance articles under the titles "Your Money Matters," and "Getting Started."

The [www.usatoday.com](http://www.usatoday.com) website mentioned earlier includes both current and past articles on a broad range of retirement and investment subjects relevant to the idea and strategy of "harvesting."



AARP ([www.aarp.org](http://www.aarp.org)) and the National Council on the Aging ([www.ncoa.org](http://www.ncoa.org)) have websites that include information on retirement planning and regulations.

The International Society on Retirement Planning ([www.isrp.org](http://www.isrp.org)) offers information and books on general financial life planning.

### *Choosing and Using Professional Financial Advisors*

A professional financial planner can assist you with asset management and financial planning. For example, a financial planner can help you prepare a financial plan that anticipates future expenses such as long-term care. With your planner, you can determine if you should consider long-term care insurance. Such a professional can also consider tax issues and help guide you in the best ways to pass on your assets through estate and trust planning.

People who call themselves “financial planners” really offer different kinds of services, from basic investment advice, to how to structure investments for retirement, to tax planning and estate planning advice. There are also several different professional associations of financial planners, and several different “designations” or certificates – that may either help or confuse you.

Here are a few basic principles:

(1) Trust: the most fundamental issue is that you trust the advisor. How he or she creates that trust is a complex issue. One thing you can do is to be informed and be prepared. The more you learn in advance, the better you will be able to ask questions, and then evaluate and trust the answers and the advisor.

(2) Know what you are buying: If the financial planner offers “free advice” on a continuing basis, be skeptical. That is, if the planner's income is based on the commissions he is making on the advice that is “freely” given, then the advice is not so free after all. Typically, choose a “fee-only” advisor rather than a “commission-based” advisor.

(3) Interview several advisors; ask your friends; check with local registries for complaints. Ask if he or she makes commissions on the investments, funds, stocks, policies recommended and if you are free to buy things not on the advisor's "preferred lists"?

You may want to look for CFP (Certified Financial Planner) or ChFC (Chartered Financial Consultant) designations when considering a financial planner.

1 National Center for Health Statistics, 1992.

2 Family Caregiving in the U.S., A National Survey.  
National Alliance for Caregiving and AARP. June 1997.

*National Alliance for Caregiving*  
*Members*

American Society on Aging  
Bell Atlantic  
Department of Veteran Affairs  
Glaxo Wellcome  
MetLife Mature Market Group  
National Association of Area Agencies on Aging  
Pfizer Inc.  
AARP  
The ALS Association  
American Academy of Home Care Physicians  
American Association of Geriatric Psychiatry  
American Geriatrics Society  
Assisted Living Federation of America  
Children of Aging Parents  
Gray Panthers  
National Association of Professional Geriatric Care Managers  
National Association of Social Workers  
National Council on Aging  
Society for Healthcare Consumer Advocacy  
Society for Social Work Leadership in Healthcare  
United Seniors Health Cooperative  
Well Spouse Foundation

This guide is intended to raise important issues and provide the reader with some background information on the topics it covers. It must not be construed as providing legal, financial, medical or other advice.

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